New Horizons for Family Caregiving

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Lynn Friss Feinberg, MSW
Senior Strategic Policy Advisor
AARP Public Policy Institute
Committee on Family Caregiving for Older Adults
Board on Health Care Services
The National Academies of Sciences, Engineering, and Medicine

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Families Caring for an Aging America

- Although an intensely personal issue, family caregiving has become an urgent public policy issue, linked to important social, health, and economic goals.

- The committee’s work:
  - Raises serious concerns about the state of family caregiving for older adults in the U.S.
  - Calls into question practices that assume the availability of a family caregiver without adequate support services.
Charge to the Committee

Three primary objectives:

- To assess the prevalence and nature of family caregiving of older adults
- To assess the impact of caregiving on individuals’ health, employment, and overall well-being
- To recommend policies to address caregivers’ needs and to help minimize the barriers that they encounter in acting on behalf of an older adult.
Framing the Report

- Not all older adults need assistance
  - The need for help with everyday activities is not an inevitable consequence of aging

- Not all family caregivers need help
  - Some families manage fine on their own

- Focuses on those who help older adults:
  - With any need due to health or functional limitations
  - With “high needs” – those with dementia or who need help with self-care (at least 2 ADLs)

- Covers not only gaps in health care and LTSS, but in the workplace too.
Framing the Report

- Addresses diversity in the caregiving context
  - Many faces of caregiving
    - Multicultural, LGBT community
    - Differing religious beliefs, native languages
- Recognizes caregiving crosses the lifespan
- Uses certain terminology
  - Does not use the term “informal” to describe family caregivers
  - Tends to use “person” rather than “patient” when referring to the older adult
Social and Demographic Trends Foretell a New Reality

- **Historic demographic changes**
  - In 2012, 43.1 million adults age 65+ (13.7% of U.S. population)
  - By 2030, 72.7 million adults age 65+ (>20% of U.S. population)
  - Increasing diversity but national surveys are not powered for subgroup analyses

- **Fastest growing cohort of older adults are those age 80+**
  - In just 10 years (2026) the leading edge of the baby boomers will enter their 80s—when people are most likely to have a physical or cognitive impairment
  - As a result, the demand for daily assistance is growing rapidly

- **The gap between the demand for and supply of family caregivers is increasing**
  - The size of American families is shrinking and the makeup of families is changing
Family Caregiving in the “Old Days”
The “New Normal”
Changing Family Structures and More Women Working

- High rates of divorce
  - Divorce rate of 50+ pop. doubled between 1990 and 2010

- More singles
  - 1 in 3 baby boomers is single today—compared to just 1 in 5 in this age group in 1980

- Fewer adult children
  - % of frail elders (age 85+) without any surviving children is projected to increase from 14% (2010) to 21% (2040).

- Increasing numbers of childless women
  - Nearly 20% of women are childless today; 10% in 1970

- More women in the workplace
The Family Caregiver Role is Far More Complex and Demanding Than in the Past

Family caregivers have always been the primary providers of older adults’ LTSS.

Today, they are also tasked with:

- **Being advocates and care coordinators**—navigating complex health and social service systems
- **Serving as surrogate decision makers** when an older adult loses the capacity to make important decisions
- **Managing difficult medical/nursing procedures** and equipment in the home, overseeing medications, and monitoring symptoms and side effects
Family Caregivers

- Provide emotional support and companionship
- Help with household tasks (paying bills, preparing meals)
- Carry out intimate, personal care (bathing, dressing)
- Administer and manage multiple medications and other medical and nursing tasks
- Communicate with health professionals
- Identify, arrange, and coordinate services and supports
- Hire and supervise direct care workers
- Implement care plans
- Serve as “advocate” during medical appointments and hospitalizations
- Act as “care coordinator” during transitions
You Take Care of Mom, But Who Will Take Care of You?

Caregiver Support Ratio

Systematic Barriers often Prevent Caregivers from Effectively Engaging in the Care of Older Adults

- Family caregivers interact with a wide range of professionals from physicians to care organizations
  - Yet they are often excluded from older adults’ treatment decisions and care planning
  - Even though care providers assume the caregiver is able and willing to perform essential tasks

- The organization, delivery and financing of health care and LTSS are designed to serve the beneficiary or the care recipient—not the family
  - Providers have little or no financial incentive to spend time with caregivers, seek their input, or provide the support they need to carry out older adults’ care plans
Systematic Barriers often Prevent Caregivers from Effectively Engaging in the Care of Older Adults (cont’d)

- Too often, health care and social service providers
  - Do not routinely identify or assess family caregivers’ availability, capacity, and willingness to assume critical responsibilities
  - Do not seek critical health information about the older adult from the family member
  - Do not ask about the family caregivers’ experience of care

- Other barriers include:
  - Payment rules that discourage provider interactions with family caregivers
  - Misinterpretation of HIPAA privacy rules
  - Lack of training in family systems, and to work effectively with the family
Families Caring for an Aging America: An Urgent Need for Action

- Even the basic structure of the workplace has not kept pace with the changing American family, the aging of the population, and the economic realities of modern life.

- The increasingly complex care needs of older adults with health and functional limitations require a new vision and a new paradigm for the organization, financing, and delivery of caregiver support services.
Families Caring for an Aging America: A Vision for the Future

No less than a transformation in policies & practices resulting in a society in which family caregivers:

- Have their own health and well-being considered
- Have rights and protections in health care, LTSS, and in the workplace
- Have their preferences, needs, and strengths recognized and supported by health and social service professionals
  - to provide high-quality, culturally appropriate, person- and family-centered services
- Are supported as caregiving changes and evolves
  - in response to shifting demographic, social, technological, and economic circumstances.
Families Caring for an Aging America: Recommendations

The focus of the nation’s health care reforms should change from person-centered care to *person-and family-centered care*

- Taking into account both the individual and the family

The Committee calls upon the Administration that takes office in January 2017 to take steps to address the health, economic, and social issues facing family caregivers of older Americans.
Families Caring for an Aging America: Recommendations

1. The Secretary of HHS—working with the Secretaries of Labor and Veterans Affairs and others—should create and implement a National Family Caregiver Strategy that includes:

A. Effective mechanisms to ensure that family caregivers are routinely identified, and their needs are assessed and supported—in the delivery of services to older adults who rely on help

B. Medicare and Medicaid payment reform to motivate providers to engage family caregivers effectively

C. Training of health care and social service providers to recognize, engage and support caregivers
Families Caring for an Aging America: Recommendations (cont’d)

National Family Caregiver Strategy that includes:

D. Dissemination and funding for evidence-based caregiver services

E. Evaluation and adoption of federal policies that provide economic support to working caregivers

F. Expanded data collection to improve reporting and analysis on the experience of family caregivers

G. A multi-agency research program to evaluate caregiver interventions in “real-world” community settings and across diverse conditions and populations.
2. States that have not addressed the needs of family caregivers of older adults should learn from the states that provide services and supports to caregivers—and implement similar programs.

3. The Secretaries of HHS, Labor, and VA should work with leaders in health care and LTSS, technology, and philanthropy to establish a public-private innovation fund to accelerate the pace of change.

4. All the above actions should explicitly address the diversity of older adults and their family caregivers.
“What we need… is for our nameless problem to be plucked out of the realm of the personal and brought into full public view, where help can find us.”

Questions?

Lynn Friss Feinberg
lfeinberg@aarp.org
202-434-3872

@FeinbergLynn

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